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Prostate Cancer Knowledge and Decision Making Among African-American Men and Women in the Southeastern United States

Otis L. Owens, PhD^{1,2}, Dawnyéa D. Jackson, PhD^{2,3}, Tracey L. Thomas, MA, MS³, Daniela B. Friedman, PhD^{2,3}, and James R. Hébert, ScD^{2,4}

¹College of Social Work, University of South Carolina, Columbia SC, 29208

²Statewide Cancer Prevention and Control Program, University of South Carolina, Columbia SC, 29208

³Department of Health Promotion, Education, and Behavior, University of South Carolina, Columbia SC, 29208

⁴Department of Epidemiology & Biostatistics, University of South Carolina, Columbia SC, 29208

Abstract

This study used multiple methods for assessing African-American (AA) men's and their female relatives, friends, and significant others' knowledge and cancer-related decision-making practices within the context of a prostate cancer (PrCA) education program. Data were collected from 81 participants using qualitative focus groups and 49 participants also completed quantitative pre/post surveys. Findings showed that men often relied on their female "significant other" and doctors for guidance on cancer-related decisions. Women described their role in assisting with their male partners' cancer decisions. AA men's and women's knowledge scores increased between pre- and post-tests which can indicate a greater likelihood of future participation in informed cancer-related decision making. Also, using multiple methods in formative research can provide relevant information for developing effective cancer-related interventions.

Keywords

African American; cancer research; decision making; prostate cancer; mixed methods

Introduction

African Americans (AAs) are more likely to develop and die from cancer than any other racial or ethnic group. Race and ethnicity are strong predictors of the stage at which cancers are diagnosed and are typically later-stage cancers among certain ethnic groups, including AA populations (Arbes, Olshan, Caplan, Schoenbach, Slade, & Symons, 1999; Hoffman, Gilliland, Eley, Harlan, Stephenson, Stanford, Albertson, Hamilton, Hunt, & Potosky,

Corresponding Author: Daniela B. Friedman, PhD, Associate Professor, Department of Health Promotion, Education, and Behavior, Core Faculty, Statewide Cancer Prevention and Control Program, Arnold School of Public Health, University of South Carolina, 915 Greene Street, room 235, Columbia, SC 29208, USA, tel: 803.576.5641; fax: 803.576.5624; dbfriedman@sc.edu.

2001). These racial health disparities can be attributed to factors such as limited prevention practices (e.g., healthy eating and regular exercise) and poor access to cancer information and healthcare resources (Arbes et al., 1999; Hoffman et al., 2001). For many cancers such as those of the breast, cervix, and colon, the American Cancer Society (ACS) has issued recommended routine screening guidelines (American Cancer Society, 2013). Due to controversies in the utility of prostate specific antigen (PSA) testing particular, screening for prostate cancer (PrCA) has proven to be very controversial (U.S. Preventive Services Task Force, 2011; Andriole, Crawford, Grubb, Buys, Chia, Church et al., 2009; Barry, 2009; Schroder, Hugosson, Roobol, Tammela, Ciatto, Nelen, et al., 2009; Smith, Cokkinides, & Brawley, 2012).

PrCA is the number one non-skin cancer among men of all races, and AA men are significantly more likely to develop and die from the disease than European-American (EA) men (American Cancer Society, 2013). This racial disparity is 50% more extreme in South Carolina (SC) than the country as a whole (Drake, Keane, Mosley, Adams, Elder, Modayil, Ureda, & Hebert, 2006). Although there is no specific cause of PrCA, biological, socio-cultural, and socioeconomic factors that have been linked to the excessive burden of PrCA on AA men, including genetic predisposition (Haiman, Chen, Blot, Strom, Berndt, Kittles, Rybicki, et al., 2011; Odedina, Akinremi, Chinegwundoh, Roberts, Yu, Reams, Freedman, et al., 2009), lack of access to healthcare (Chornokur et al., 2011; Du, Fang, Coker, Sanderson, Aragaki, Cormier, et al., 2006), limited information about the disease, and unhealthy lifestyles (e.g., poor diet and limited exercise) (Ma & Chapman, 2009). Within the southeastern U.S. (e.g., Georgia, South Carolina), in particular, AAs tend to have a higher mortality from most cancers than people in other parts of the country, including for prostate, cervical, and oral cancers. The high mortality-to-incidence ratios may be explained by the poor access to and use of healthcare and other socioeconomic/sociocultural factors (e.g., low income, dietary intake) (Hébert, Daguise, Hurley, Wilkerson, Mosley, Adams & Bolick-Aldrich, 2009; Wagner, Hurley, Hébert, McNamara, Bayakly, & Vena, 2012). In addition, since age significantly increases a man's chance of developing PrCA, older AA men are at the highest risk. For example, statistics from the National Cancer Institute's Surveillance, Epidemiology and End Results database show that an AA man who is 30 years old has a .03% chance of developing PrCA within the next 10 years, whereas an AA man who is 60 has about a 10% chance of developing the disease within the same time span (National Cancer Institute, 2012). However, 30 and 60 year old White men have .01%, and 2% chances respectively of developing PrCA within the next 10 years (National Cancer Institute, 2012). Despite these disparities, routine PrCA screening is not currently being recommended by major health and cancer agencies. The decision to not recommend routine screening is based on a substantial body of scientific evidence that shows PrCA screening (particularly using PSA) does not effectively reduce PrCA mortality (Andriole, et al., 2009; Schroder et al., 2009).

Two of the largest and most recent PrCA screening trials have been the center of the screening controversy and also lacked adequate AA participation (Andriole et al., 2009; Schroder et al., 2009). The U.S. study, titled "Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial on Prostate Cancer Mortality," was a 10-year, multi-center, randomized trial among 76,693 American men and concluded that men who received PSA

and digital rectal exams did not significantly lower PrCA mortality rates when compared to men who did not receive these exams (Andriole et al., 2009). “The European Randomized Study of Screening for PrCA, “ also a 10-year study conducted among 182,000 men to determine the effectiveness of the PSA exam for reducing PrCA mortality, found that the PSA was effective at significantly reducing the rate of PrCA mortality among study participants, but with the detriment of overdiagnosing PrCA. Overdiagnosis is a serious concern because it can lead men to undergo unnecessary surgeries or receive other treatments for indolent forms of PrCA which can lead to lifelong side effects (e.g. impotence, incontinence) (Welch & Albertsen, 2009). Based on the results of these two major studies and other, smaller studies, the United States Preventive Services Task Force recommends that no healthy man should receive routine screening for PrCA (U.S. Preventive Services Task Force, 2011). On the contrary, organizations such as the ACS recommend that men make informed, but shared decisions with their doctors beginning at 50 for most men and 45 for high-risk groups such as AAs) about whether or not to receive PrCA screening. The Centers for Disease Control and Prevention’s (CDC) Task Force on Community Preventive Services defines informed decision making (IDM) as: “*when an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time*” (Briss, Rimer, Reilley, Coates, Lee, Mullen, et al., 2004). In order to make an informed decision about PrCA screening, men need adequate, plain language, culturally appropriate information as recommended by Healthy People 2020 (U.S. Department of Health and Human Services, 2011) and the Institute of Medicine (Institute of Medicine, Committee on Health Literacy, & Board of Neuroscience and Behavioral Health, 2004).

Cancer-Related Decision Making

Socioeconomic status (Williams, Zincke, Turner, Davis, Davis, Schwartz, et al., 2008), level of education (Shokar, Carlson, & Weller, 2010), disease knowledge (Wray, McClure, Vijaykumar, Smith, Ivy, Jupka, & Hess, 2009), access to healthcare, health literacy (Friedman, Corwin, Rose, & Dominick, 2009b), fear/denial (Drake, Shelton, Gilligan, & Allen, 2010;), family experiences, self-efficacy (Drake et al., 2010), interpersonal skills of the physician (Reynolds, 2008), and trust in the physician or medical system (Yang, Matthews, & Anderson, 2013) can influence how individuals make decisions regarding cancer PrCA screening. Many of the aforementioned factors can also affect an individual’s help seeking behaviors. For example, previous research has demonstrated that AA men may forgo doctors’ visits because of fear and prior unfulfilling experience with a doctor (Griffith, Allen & Gunter, 2011). These limitations in doctor-patient communication can hinder the shared/informed decision-making process regarding PrCA screening desired by the ACS. In addition, this help-seeking literature indicates that overall adherence to a doctor’s advice can depend highly on both a spouse and their individual self-efficacy (Griffith et al., 2011; Drake et al., 2010). Specific facilitators of IDM and help seeking include education interventions (Drake et al., 2010; Holt, Wynn, Litaker, Southward, Jeames, & Schulz, 2009),

informed decision aids (O'Brien, Whelan, Villasis-Keever, Gafni, Charles, Roberts, Schiff, & Cai, 2009), and family support (Brittain, Taylor, Loveland-Cherry, Northouse, & Caldwell, 2012). The physician also may play an influential role in their patients' screening decisions (Smith, Cokkinides, & Brawley, 2009). However, often these decisions do not take place in the context of a shared conversation between the doctor and patient (Smith et al., 2009). Some older adults place great trust in their physician to make medical decisions such as recommendations for screening (Levinson, Kao, Kuby, & Thisted, 2005). Others often make screening decisions on their own, based on limited knowledge, or without their doctor's recommendation (Shapiro, Seeff, Thompson, Nadel, Klabunde, & Vernon, 2008). For example, one recent study showed that some older adults have adopted medical screenings as customary practices which do not require them to participate in any true "decision-making" process (Torke, Schwartz, Holtz, Montz, & Sachs, 2013).

For AA men of all ages, prior research has also demonstrated that AA women play an influential role in their cancer-related decision making, including serving as sources of PrCA information (Friedman et al., 2009b). For example, in a qualitative study of AA men, Friedman et al., 2009 found through focus groups and interviews that participants were not only reliant upon AA women (e.g., spouses, significant others, relatives) for health information, but preferred that future messages to promote IDM about PrCA be delivered through clergyman, cancer survivors, *and* women. The findings from this study and others have provided a basis for including women in our study. Using multiple methods, this formative study is one of the first to examine cancer-related decision making (specifically IDM) within the context of a PrCA education intervention for *both* AA men and women.

Conceptual Framework

The study was guided by the Charles Model of Shared Decision Making which suggests that shared decision making has four key characteristics including (1) the involvement of at least (but not limited to) two participants (i.e., patient and physician or patient and family member) (2) both parties should share information relevant to the specific cancer-related decision (3) both the patient and physician should build a consensus about the preferred screening or treatment, and (4) a joint agreement should be reached regarding a final plan of action (Charles, Gafni, & Whelan, 1997, 1999). Based on recommendations by the ACS, IDM about PrCA screening should take place within a shared context (Charles et al., 1997, 1999). Shared decisions regarding PrCA screening can result in multiple outcomes including a decision to not be screened, a decision to be screened at a later date, or a decision to be screened. Beyond the decision to be screened, an individual must also decide which screening or screenings to receive (i.e., PSA, digital rectal exam). The same model can also be used for decisions regarding cancer treatment (Charles & Gafni, 2010).

Methods

Focus Groups

All aspects of this research were approved by the university's and clinical partner's institutional review boards. We worked with our community partners at a National Cancer Institute Community Cancer Centers Program (NCCCP) and a community advisory panel in

the city of Spartanburg, South Carolina (southeast United States) to devise a participant recruitment strategy. Recruitment efforts were guided by Vesey's framework on the recruitment and retention of minority groups that involves a series of strategies such as leveraging partnerships in the community to assist researchers throughout the planning and implementation process (Vesey, 2002). The specific strategies from Vesey's framework used for this study were: 1) conceptualization, planning, and development of the recruitment plan and promotional materials in collaboration with community partners, 2) recruitment of study sample with our partners, 3) collaboratively developing study materials, contacting and interviewing the study participants, and 4) reporting findings to the community at various stages in the research process... Some of the strategies for the recruitment of our sample included the use of word-of-mouth and multi-media approaches (e.g. flyers) at a number of local venues (e.g., churches, barbershops, etc.) (Friedman et al., 2012).

Eligible participants were AA men over the age of 40 with no history of PrCA and AA women over the age of 21 with a qualifying male spouse, relative, or friend who could also participate in study. All participants were required to have English as their first language (Friedman et al., 2012). Following recruitment of participants, twenty-two, 90-minute focus groups (half with men and half with women), were conducted at a local public library (Friedman et al., 2012)

The overall aims of the qualitative component of this study were to assess AA men's and women's (1) current knowledge and attitudes regarding PrCA prevention and screening, (2) sources of health and cancer information, and (3) processes for making cancer-related decisions such as screening. The information gathered through the discussion groups was used to create a pilot education intervention focused on increasing knowledge about PrCA and IDM for PrCA screening. The discussion group protocol, co-developed by the research team, NCCCP partners, and the community advisory panel, consisted of 19 original questions, of which 14 were specifically related to PrCA knowledge and decision making. All focus groups were moderated by researchers of the same gender as the group participants. These moderators used culturally appropriate language and methods to facilitate the sessions. For example, since there is some mistrust among AAs regarding research participation (George, Duran & Norris, 2014), most moderators refrained from using the word "research" and ensured that plain language was used when explaining medical concepts and terms. Each moderator received a brief, in-person training from a senior member of the research team before implementing the first of multiple focus groups. The training reinforced basic research ethics gained through "The Collaborative Institutional Training Initiative" (CITI training), an electronic training program required prior to implementing human subjects research, and prepared the moderator for various aspects of focus group implementation such as strategies for managing deviations from the discussion topics. Each focus group was audio-recorded and professionally transcribed. An additional researcher or clinical partner was also present to serve as a note taker. In order to protect the confidentiality of the focus group participants, all names were removed from the transcripts by the transcription service and all transcripts were verified by the research team for any missed identifiers.

Prior to the focus group discussions, participants were administered an 18-item survey which collected demographic information such as income and current, preferred, and feasible (i.e. accessible) sources for health/cancer information. These multiple choice questions were developed or adapted by the research staff based on prior studies (Friedman, Corwin, Dominick, & Rose, 2009a; Friedman et al., 2009b) and through a review performed by our community advisory panel. Data from the survey were analyzed using SPSS® 18.0 (SPSS Inc., 2012) and nonparametric frequencies/percentages were calculated.

Qualitative Coding and Thematic Analysis—Preceding the thematic analysis of the focus groups, a master codebook was developed by members of the research team through an open coding process (Strauss & Corbin, 1998). During this coding process, two members of the research team independently coded one transcript from each gender group. Each researcher used the discussion guide as an initial framework. The open coding (i.e., identifying key words or potential categories in each line of the transcript) led to the conceptual organization of the data into potential themes. Following the open coding process, the researchers discussed and reached a consensus on the definition of each code which would ultimately be included in a master codebook. Based on this master codebook, which included a comprehensive list of codes, researchers re-coded all of the transcripts through an axial coding process; i.e., a method through which thematic relationships that exist between codes are identified (Strauss & Corbin, 1998). Additionally, researchers employed a constant comparison method, which involves comparing and contrasting themes across groups (e.g., differences in the attitudes of men and women regarding health screenings) (Strauss & Corbin, 1998). All coding and thematic analysis following the open-coding process was performed in NVivo® 9 (QSR, 2010), a qualitative software program.

Pilot Education Intervention Pre/Post Surveys

A pilot education intervention, developed based on data (e.g., prostate knowledge) gained through our aforementioned focus groups, was implemented with 56 (of 81 invited) participants who agreed to participate in four, one-hour, in-person group sessions over a one month period (Friedman et al., 2012). Education sessions began approximately one month following the last focus group session and were offered at multiple times and days within a given week to accommodate the varying schedules of the participants. These instructor-led sessions provided men and women with verbal and written (i.e. educational packet) information about PrCA, PrCA screening, and participation in clinical research. The topics that were covered over the four-week period were: What are risk factors and symptoms of PrCA?, PrCA screening guidelines: Should I get screened for PrCA? (screening decision making), What are clinical trials? (research participation decision making), What is informed consent?, and Talking about prostate cancer: Overcoming barriers to discussing PrCA. In addition to the education sessions, each participant received a short reinforcing educational message (e.g., “The PSA blood test and digital rectal exams are used to identify prostate cancer. The PSA test is not 100% accurate. Be sure to talk to your doctors about screening options”) each week based on materials presented during the education session from the previous week. The four messages were disseminated through three channels: text message, email, or post-card based on the preference of the participant. Prior to and following the completion of the four education sessions, participants were asked to complete

a 75-question survey to assess their change in PrCA and clinical trial-related knowledge, perceptions, and behaviors. Thirty-six of these questions assessed prostate knowledge and cancer-related decision-making practices. These questions were based on existing instruments (Kim, Knight, Tomori, Colella, Schoor, Shih, et al., 2001; Murray, Pollack, White, & Lo, 2007) and covered topics such as prostate anatomy (e.g., “The prostate is the size of a walnut” - yes, no, I don’t know) and prior conversations with doctors about screening (e.g., “My doctor and I made a decision about prostate cancer screening” - Strongly Agree, Agree, Neutral). The survey instrument was reviewed for content validity by an expert research panel not affiliated with the project and pilot-tested by multiple members of the community advisory panel. In total, 49 of the 56 participants (87.5%) completed both pre- and post-test surveys. Participants received a monetary incentive following the completion of the pre-test and an additional incentive following the completion of the post-test survey.

Results

Participant Demographics

Eighty-one men and women participated in this research (43 men, mean age 51.0 years and 38 women, mean age 50.3 years). Almost half of the participants, (48.8% of men and 44.7% of women) reported being married. Over half were employed full (44%), fewer worked part time (10%) or were retired (16%) or unemployed (11%). The majority of participants (84%) had household incomes between \$20,000 and \$59,000. In addition, 15% had less than a high school education, 65% had a high school diploma or completed some college, and 20% had completed college or an advanced graduate degree. More detailed demographics (stratified by gender) are described elsewhere (Owens, Jackson, Thomas, Friedman, & Hebert, 2013).

Focus Group Themes

Prostate Cancer Knowledge

Symptoms: AA men’s and women’s PrCA knowledge was limited. Participants were familiar with some symptoms for PrCA, but most often referred to frequent or difficult urination. For example, when a male participant was asked about the symptoms for PrCA, he responded, “I know that it’s going to the bathroom a lot at night. I know that’s one of the symptoms.” Female quotes regarding symptoms for PrCA were similar. A female participant stated, “I heard that they [men with prostate symptoms] have problems urinating. It’s either like you have to go and you can’t or you go every few minutes.” Other symptoms reported by men and women were erectile dysfunction and enlargement of the prostate. Symptoms not mentioned were painful ejaculation, blood in urine or semen, pain in the lower back, hips, or thighs. In addition, none of the participants mentioned that some men with PrCA may not have any symptoms present prior to diagnosis.

Women were more likely to report not having any knowledge about PrCA including symptoms, risk factors, or screenings than men. Many of these women expressed the need for more education. The following quotes represent their self-reported lack of prostate knowledge:

- “I don’t even know what area [prostate location]. I know it probably is a sexual area, but what area? What does it affect? What happens?”
- “No, I don’t know too much about it either. I know my brother ...he gets treated for the high, can’t even call it now, you know, what is it, PSI, PSA? PSA, yeah.”
- “I really don’t know any signs, I mean, that’s what I’m here to learn today, to be educated on prostate cancer.”
- “What does the colonoscopy screening do – what all does it detect?”

Risk Factors: When asked to describe potential risk factors for PrCA, both AA men and women mentioned the role of poor diet and lack of exercise. One male participant reported, “One of the things that ...causes it [prostate cancer] is, of course, diet.” Similarly, female participants stated, “...especially down here [South], they got a lot of sausages and fatty foods, I think that would have a lot to do with it,” and “things such as being inactive, so lifestyle can contribute to it as well.” Other risk factors mentioned less often were smoking, the stressors of daily life, and older age.

There were however, some misperceptions regarding the risk factors for PrCA which were more commonly stated by female participants. For example, a female participant asked researchers if and how sexuality was linked to the risk of developing PrCA. She stated, “I know some young men who are actively gay, homosexual, whatever. Is that a factor in the process of anything that contributes to any part of that?” A second female participant also posed a question which referred to the role of the lack of sexual activity in explaining the perceived behavior of an acquaintance with PrCA. She stated, “Before he died, that man went crazy, they said, because he could no longer have sex. So it's got something to do with sex too, right?”

Perceived Highest Risk Groups: Participants’ perceptions about who was at the highest risk for PrCA were categorized into three groups: AAs, older adults, and those individuals who lived unhealthy lifestyles (e.g., high-fat diet, lack of exercise). Being an AA was the most common response when asked about the population they perceived to be at the highest risk for PrCA. This perception was most often reported by men. When asked about who they perceived was at the highest risk for PrCA, male participants reported the following:

- “I know it’s the leading death of black men, that’s about all I know.”
- “I just hear of it being an African American. I never thought anything else other than a large majority who get prostate cancer in America.”
- “Where I live, a black community, black people, basically.”

Men and women were equally likely to report age as a risk factor for PrCA. In particular, they often mentioned that the older generation was at the highest risk for the disease. Specific ages were typically not used to define the term “older generation,” but could begin anywhere between 45 to 55 years of age according to participants who did include an age in their response. For example, when asked who she thought was as the highest risk, a female participant responded, “I’m gonna say 45 and over.” On the other hand, a male participant

responded "... everyone is at risk, but African American is one, and then 55 and older." However, most participants responded similar to the following female participant who stated, "I think the older generation 'cause back in the old days a lot of old persons didn't go to the doctor."

Those who make poor lifestyle decisions also were reported only by AA males as a population at the highest risk for PrCA. One male participant stated "individuals [that]... don't have a good diet as far as eating healthy and many other factors" were at the highest risk for PrCA while other male participants had the following representative responses related to inactive individuals: "A person that don't exercise and take care of themselves." and "I would say it's an obese person more likely."

Participants' perceptions for why AA men are at the highest risk for PrCA were generally related to their poor diets, lack of routine doctor visits, family history of disease, and the quality of accessible medical care. Men and women equally reported diet as the most likely contributor to the high risk of PrCA among AAs. In many instances, participants attributed some AA dietary behaviors to culture. When asked why he thought AAs were at the highest risk for PrCA, a male participant said, "Because I hate to say it, a white man will go on a diet if the doctor asks him to go on a diet. A Black American, he's gonna eat what he wants to." The lack of AA visits to the doctor was also equally perceived by men and women as a contributor to the higher incidence of PrCA. A female participant stated, "I think it's probably because a lot [of men] don't go regularly to the doctor." Heredity also was perceived as a cause for AAs' high risk for PrCA. For example, a male participant stated, "It's getting passed down to us through our fathers, from their fathers, on." In addition, some male participants perceived that the quality of care that AA men in general receive is inferior to that received by their white counterparts. Two representative quotes were: "I think as men, whites got better doctors, and I think they're kind of keeping it a little quiet. And that's the reason our statistics is so high, you know, on everything" and "We don't get the quality attention as the white man would get going to the doctor."

Cancer-related Decision Making

Overall, men's comments about how they made cancer-related decisions such as those about PrCA screening varied but often related to a decision by their doctor, a requirement of a job, having knowledge about the effects of PrCA, or being influenced by a family member. When asked how he made decisions about whether or not to receive PrCA screening, one participant discussed how his doctor recommended (based on his age) that he receive an annual prostate exam. He stated, "I think it was my doctor. My doctor said I have to have this prostate examination each year at my age."

Men often reported relying on their female significant other and the doctor for guidance on preventive behaviors such as healthy eating. Women also commonly described their role in choosing the types of foods they consumed, controlling the way in which foods were prepared (e.g., baked vs. fried), and making decisions about the time of day that men ate. In some instances, women and men also described their behaviors as being performed in a team capacity where both individuals served as a support for the other. For example, a female participant stated, "We're both overweight, so we have been going to the gym. And, for me,

it's easier to eat healthy, for him, he doesn't necessarily eat as healthy but he likes to workout. So we've learned how to combine the two." Similarly, a male participant stated, "We're [wife and I] trying to work out and lose weight together ... she's my dietician pretty much." Furthermore, all men agreed that women provided positive support for them regarding IDM. When one male participant was asked whether he felt positive support from his wife, he stated "My wife gives me 100 percent support ... if I'm making the right choice. ... but if she thinks I'm not making the right choice we're gonna discuss it." A second male participant agreed, stating, "I think when you have someone that has your ... best interest at heart ... that kind of gives you a piece of mind."

Pilot Education Intervention Pre/Post Survey Results

Prostate Knowledge—AA men's and women's prostate knowledge scores increased between pre- and post-test on all variables, but only some changes in knowledge were statically significant. Given that this was a pilot intervention (e.g., small number of participants), it was not expected that the results would meet the conventional measures of significance. When scores were stratified by sex, there were no items on which men or women only exhibited statistically significant increases in knowledge. Items on which all participants demonstrated significant increases in knowledge were regarding: (1) location of the prostate (2) decrease urine flow as a symptom of PrCA (3) pain or burning in urine as a symptom of PrCA (4) back pain as a symptom of prostate cancer and (5) current ACS guidelines about PrCA which suggest that AA men begin discussions about prostate cancer screening with their doctor at 45 years of age. Men and women also had a marginally significant increase in knowledge regarding men with a family history of prostate cancer being at higher risk for the disease (See Table 1).

Cancer-related Decision Making—Participants were asked about IDM within the context of the PrCA intervention. Most men and women reported having enough information to make a decision about their health either all (Pre-test: 22%; Post-test: 29%) or most (Pre-test: 45%; Post-test: 51%) of the time. In addition, over half (51%) of participants also reported at pre-test that their doctor discussed cancer screening options with them and together they made a shared decision. The remainder reported their doctor kept them informed but they made decisions based on what was best for them (30%) or their doctor told them the pros and cons and then they decided what to do on their own (19%). At post-test there was (1) a slight (10%) decrease in the number of people who reported shared decision making with their doctors, (2) and a 12% increase in people who allowed the doctor to make the final decision about cancer screening, and (3) a 10% increase in those not discussing health with their doctor. However, shared decision making remained the most reported form of decision making. Furthermore, there was a moderate increase between pre- and post-test in the number of men and women who reported that their doctor asked them how they wanted to be involved in the decision about getting screened. When asked if there was anyone besides their doctor involved in decision-making practices, 55% at pre-test and 74% at post-test answered yes. Spouses or significant others (67%) were the most commonly mentioned individuals (other than doctors) involved in decision making of men or women, followed by children (daughter or son), (17%), mother (14%) or friend (3%).

Discussion

This study utilized two methods (qualitative focus groups and quantitative pre/post survey data), to explore how AA men and their female counterparts understand and make decisions, particularly with regard to cancer and PrCA screening (men). The use of multiple methods is similar to other public health interventions involving cancer decision making (Esbensen, Thome, & Thomsen, 2012; Garcia, Borràs, Milà, Espinàs, Binefa, Fernández, Farré, Pla, Cardona, & Moreno, 2011; Sawka, Meiyappan, David, Straus, Gafni, Brierley, Tsang, Rodin, Rotstein, & Ezzat, 2011) and is important because these methods can provide a means to validate and strengthen study findings (Guion, Diehl, & McDonald, 2011). Consistent with prior research, AA men and women are receiving information from a variety of sources including their spouses or significant others (Levinson et al., 2005; Nussbaum, 2000). Men and women also reported working as a team to serve as a support system for one another. In addition, the majority of both men and women (74%) reported having assistance from another person (most often their spouse or significant other) when faced with making a cancer-related decision. Others studies that involve dyads (male-male, female-male, or female-female) have also shown that dyadic social support among older adults can lead to better outcomes such as increased self-efficacy and lower depression after prostate surgery or facilitate decision making including participation in research (Chadiha, Morrow-Howell, Proctor, Picot, Gillespie, Pandey, & Dey, 2004; Weber, Roberts, Yarandi, Mills, Chumblor, & Wajzman, 2007). Furthermore, participants reported that motivators for decisions to lead a healthier lifestyle could be having an existing chronic disease or being older (commonly associated with increased health cognizance).

The focus group data (especially at post-test) shows that decisions made specifically about PrCA screening were most often recommended by a doctor or made solely by the individual. We believe that the decrease in the number of people who reported shared decision making with their doctors and the increase of those who either let the doctor make the final decision or made their own decision were found because participants did not have a thorough understanding of the shared decision making process prior to our education session. In addition, though the pre/post survey data demonstrated that most participants felt well informed about cancer prior to a doctor's visit and many participants report being involved in a shared IDM process with their doctor, there were almost an equal number (49%) of individuals who were not fully informed about the risks, benefits, and uncertainties of PrCA screening and also reported not participating in the IDM process with their doctor regarding screening (including PrCA screening) as recommended by the ACS. These findings are salient because they not only elucidate the need for access to comprehensible prostate cancer information, but clear understandings of what constitutes shared IDM. While men and women had limited knowledge of some aspects of PrCA (e.g., symptoms), scores for men and women increased significantly following the PrCA education intervention. Therefore, we believe that participants will be equipped to directly (men) or indirectly (women) participate in the IDM process as recommended by ACS. The success of the intervention can be partly attributed to the formative and collaborative nature of our study. In our approach we actively involved the community in a discussion to find out what they wanted to know about various elements of prostate health and incorporated these into our intervention

(Friedman et al., 2012; Owens et al., 2013; Thomas, Owens, Torres, Friedman, & Hebert, 2012). This formative approach is being used increasingly and successfully in public health research (DeJoy, Padilla, Wilson, Vandenberg, & Davis, 2013; Haerens, De Bourdeaudhuij, Eiben, Lauria, Bel, Keimer, et al., 2011; Wells, Quinn, Meade, Fletcher, Tyson, Jim, & Jacobsen, 2012). In addition we have continually collaborated with community and clinical partners who have established relationships with the study community. These partners have been involved in every facet of the research spanning from the conceptualization of the research to and the development of peer reviewed publications. Their commitment to the community and the research process has not only led to measureable benefits to the community (e.g., increase PrCa knowledge), but may also lead to additional resources in the future (e.g., access to prostate nurse navigator) through a sustainable partnership (Friedman, Owens, Jackson, Johnson, Gansauer, Dickey, et al., 2014).

Limitations and Implications

While this multiple methods study provided the research team and its community partners with a wealth of information, the study is not without limitations. The sample consisted of a small number of AA men and women from one southern city. Therefore, the results from this study may not be generalizable to AA men and women in other parts of the state or other regions of the U.S. In addition, the results cannot be generalized to other racial and ethnic groups.

Despite these limitations, this study provided valuable information that can help researchers and other community members understand how AA men and women make cancer-related decisions. Including both men and women in our study provided us with a more holistic perspective of AA families' decision-making practices. The multiple methods approach greatly strengthened the study and allowed us to obtain comprehensive data on the decision making of AA men and women. Using multiple methods can increase the validity of formative research findings and ensure that phenomena that could not be discovered using only one method are identified for future intervention development. Our formative (qualitative) data provided in-depth understanding of AAs' perceptions and knowledge needs beyond data that would have been collected by quantitative data alone. However, there were similar overall results from both qualitative focus groups and quantitative surveys which helped validate our findings (e.g., lack of cancer-related IDM). In addition, specific findings from this exploratory study support the need for public health programs inclusive of promoting informed IDM and generating evidence to allow for sufficient scientific data to warrant a strong, congruent PrCA screening recommendation among national health organizations. Future community-based formative research and intervention work should consider using a similar multiple methods approach to further explore the role of social, cultural, and contextual factors on cancer-related screening IDM to obtain a more complete picture of IDM in AA communities.

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Table 1

Pre/Post Knowledge Results from Pilot Intervention Survey

Select Survey Items**	All Participants (N=49)*	
	Pre-Test	Post Test
(1) The prostate is between the bladder and penis.	25/49 (51.0%)	43/47 (91.0%)
(2) Decreased urine is a symptom of prostate cancer.	23/49 (47%)	46/49 (94%)***
(3) Pain and burning in the urine is a symptom of prostate cancer.	18/49 (37%)	37/49 (76%)***
(4) Back pain is a symptom of prostate cancer.	13/49 (27%)	32/49 (65%)****
(5) Current ACS guidelines about PrCA suggest that AA men begin discussions about prostate cancer screening with their doctor at 45 years of age.	34/47 (72%)	45/49 (92%)***
(6) A man with a family history of prostate cancer is at a higher risk of getting the disease.	22/49 (45%)	31/49 (63%)

* 56 individuals participated in the education program. 49 people completed both pre/post surveys. Data from the 49 participants are reported in the table.

** Response options for each of these items was yes, no, or unsure. These results also only reflect those participants who answered the questions correctly at pre- and/or post-test.

p<.05

p .001